Indigenist Critiques of Biocolonialism

We are not opposed to sharing with humanity. What we oppose is being exploited when our poverty is not resolved.  

– José Acosta¹

At the June 1993 session of the United Nations Commission on Sustainable Development, indigenous representatives described the Human Genome Diversity Project (HGDP) as “very alarming”: “We are calling for a stop to the Human Genome Diversity Project which is basically an appropriation of our lives and being as indigenous peoples.”² They also raised concerns about patenting and commercial exploitation: “How soon will it be before they apply for IPRs [Intellectual Property Rights] to these genes and sell them for a profit?”³ That same year, a workshop on the “Ethical and Human Rights Implications” of the HGDP convened, during which it was suggested that sampling begin “with the least politically risky groups . . . If the Project does not proceed carefully and properly, it could spoil the last good opportunity to obtain some of this data.”⁴ What were “proper procedures?” Paul Weiss, an anthropologist, proposed the following strategy, according to the summary report:

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“Immortalization” can be a very sensitive term and should be avoided when talking about the intended creation of cell lines. (Someone suggested using “transformation,” the standard European practice.) Whether to tell people what you intend to do, as a technical matter, is a difficult question.5

As one favorable article in the journal *Nature* understated: “the [Diversity Project] has insufficiently anticipated the inevitable objections to it.”6 Numerous critiques in numerous fora were advanced throughout the 1990s, contesting what has been described in previous chapters as the legacy of value-neutrality and value-bifurcation: the deflection of normative criticism away from the production of scientific knowledge and its restriction to dilemmas of knowledge application; the reduction of ethics to a supplementary, or compensatory activity, tacked on to the uses of science, and focused exclusively on developing measures to mitigate undesirable effects; and the attendant displacement of reflection on how relations of power factor practically and morally into both. These critiques were a means of revealing and resisting the implications of biocolonialist practices for indigenous peoples, cultures, and resources. They openly and repeatedly undermined the effort of Diversity Project proponents to abstract, isolate, and immunize the Project from history. As Mick Dodson noted, in its early incarnation, the Diversity Project described threatened peoples as “‘Isolates of Historic Interest’ or ‘IHIs’ . . . not peoples who have been abused and violated to the point of extinction; not peoples who are in desperate need of respect and support to survive in their integrity; but ‘Isolates of Historic Interest.’”7

**Contesting the Diversity Project**

The controversy over the HGDP raised crucial issues about the role of power in the formulation, pursuit, and justification of western scientific research. A main venue for much of the debate it provoked was a listserv, where a virtual struggle was waged. Administered by Gary Trujillo from

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5 Paul Weiss, as cited in ibid., 6.
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Texas A&M University, Native-L was a high-volume forum dealing with indigenous issues across the world. The depth and force of indigenous opposition to the Diversity Project apparently took many by surprise. “I don’t think it initially crossed anyone’s mind that [the Diversity Project] would be controversial,” one supporter notes.\(^8\) Such surprise stems from a failure to contextualize the Diversity Project, to situate it in the broader cultural politics in which practices of western science – especially those impacting indigenous peoples – are, and have historically been, steeped. Indigenist critics are attentive to this. Historically informed and politically aware, they are filled with the hard lessons learned from prior encounters with western science and acutely conscious of social and power relations. Okanagan activist Jeannette Armstrong, for example, preceded her discussion of the Diversity Project by reviewing how indigenous genetic resources have been exploited in the name of pharmaceutical science.\(^9\) Debra Harry, director of the Indigenous Peoples Council on Biocolonialism, and Aroha Te Pareake Mead, the Foreign Policy Convenor and Deputy Convenor of the Maori Congress, also situated it in the cultural politics governing the interaction of western science and indigenous peoples, as did many other indigenist critics.\(^10\)

By contrast, Diversity Project proponents tended to proceed as though it were possible to remove and insulate the Diversity Project from history and politics. The hand-washing comment of the frustrated geneticist that “We are scientists not politicians” is typical, and has been met with a trenchant response: “As if opening the veins of indigenous peoples of the world might not constitute a significantly political act.”\(^11\) The skirting of moral issues and political realities was striking in the Diversity Project’s Frequently Asked Questions (FAQ), which stated that if sampling was too long delayed, some human (i.e., indigenous) groups might disappear as

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discrete populations “usually through urbanization or other forces leading to the loss of their language or the other characteristics that identify them as a separate group.”\textsuperscript{12} This convenient, politically numb, dismissal of the many ways in which oppression historically has impacted, and continues to impact, the survival and well-being of indigenous peoples is the rule rather than the exception in the writings of Diversity Project proponents. “Nowhere in the [Diversity Project] literature,” Aroha Mead asserts, “Have I ever sighted acknowledgement of the extent and effects of the first wave of colonization . . . have they even thought about political distinctions or, in pursuit of a ‘pure scientific goal,’ are they ignoring the social, political, economic, cultural realities?”\textsuperscript{13}

The “inevitability” of the Project went unquestioned in the HGDP literature, the discussion always being “framed in an assumption that the Diversity Project is inevitable and its critics had best join the parade or lose any opportunity to improve its operation.”\textsuperscript{14} Over the course of the decade, the HGDP rolled relentlessly on, despite massive, emphatic, and reiterated objections from the major indigenous organizations at the international, national, and local levels. At a heated meeting in Guatemala, Henry Greely – the Stanford Law Professor who chaired the Ethics subcommittee of the North American HGDP – admitted to his critics that the West and western science had done terrible things to indigenous peoples, but . . . that our project was different – that we were trying to do things right . . . I encouraged them to become involved in order to help us insure that the Project did not harm their interests.\textsuperscript{15}

He acknowledged indigenous peoples’ deep weariness of being studied but did not skip a beat in his support of it. The Diversity Project’s indigenist critics were not at all convinced “that a worldwide campaign to collect


\textsuperscript{13} Mead, “Letter from Aroha Mead.”


\textsuperscript{15} Henry Greely, “Letter from Hank Henry Greely, North America HGDP Ethics Committee Chair, to Ken, HGDP Visits Guatemala” (December 16, 1993 trip report). This is no longer available on the former Rural Advancement Foundation International (RAFI) Web site. A copy is on file with the author.
indigenous human cell lines is inevitable.” The HGDP itself was derailed as a result of their opposition, but the ultimate, long-term success of such resistance remains to be seen.

Planned or Under Way?

One of the more striking features of the public debates between HGDP critiques and Henry Greely and other HGDP advocates was the

16 Ibid.
17 The exact status, however, of the HGDP currently remains in question, as is confirmed by two recent studies. Joanne Barker, for example, notes that although the HGDP was seriously impeded by the National Research Council (NRC) report, and although its proponents insist it has discontinued,

its website is still operating, with frequent updates, suggesting that the HGDP may not be formalized as such but its participants are still moving on with their plans. The Indigenous People’s Coalition on Biocolonialism . . . has been informed on numerous occasions in recent years that indigenous communities in North America have been approached by HGDP participants. (Joanne Barker, “The Human Genome Diversity Project,” Cultural Studies, 18:4 (2004): 598)

The HGDP is listed on the Web site of the Morrison Institute for Population and Research Studies at Stanford University (www.stanford.edu/group/morrinst/hgdp.html).

Jenny Reardon draws attention to the hidden, if not secret, nature of ongoing research in human genetic variation:

Much genomic research on human diversity moves forward today in private companies or in an ad hoc way, accompanied by little or no debate. This should be cause for great concern . . . one organizer describes . . . a “morphed” Human Genome Diversity Project. Although this proponent of the initiative was willing to tell me of its existence, he was unwilling to provide any details. He justified his silence by stating the project had very little money, and it was still too early in the planning phase to say anything about it. (Personal correspondence with author, November 2003). (Race to the Finish: Identity and Governance in an Age of Genomics (Princeton, New Jersey: Princeton University Press, 2005): 166, 208)

She adds that for genetic variation research to proceed “without a broad-ranging societal debate about race, identity and authority . . . threatens to reproduce structures of race and racism that we seek to transform and overcome in domains other than the scientific.” (166)

The Indigenous Peoples Council on Biocolonialism (IPCB) lists the many respects in which the National Geographic Society’s Genographic Project would seem to be the, or at least a, successor project to the HGDP. “The main significant difference is that the Genographic Project has secured private funding, and thus does not have to undergo the same depth of public scrutiny. The absence of federal oversight raises the level of risk, leaving indigenous peoples with fewer mechanisms for accountability.” (Debra Harry and Le’a Malia Kanehe, “Genetic Research: Collecting Blood to Preserve Culture?”, Cultural Survival Quarterly, Issue 29.4 (January 6, 2006). See also the Web site for IPCB at www.ipcb.org.) The Genographic Project intends to collect 100,000 indigenous DNA samples, hoping to reconstruct ancient migrations. See Amy Harmon, “DNA Gatherers Hit Snag: Tribes Don’t Trust Them,” The New York Times, 10 December 2006.
latter’s constant reiteration that the HGDP “remains in its planning stages.” Although the Human Genome Project (HGP), in 1994, had been functioning for a number of years and had significant funding, the HGDP, it was emphasized, was not underway. It “is a PROPOSAL,” Greely emphasized. A series of qualifiers threads its way through these reassurances, however: “the Project is still largely in the planning stage”; “In most of the world... it remains entirely in the planning stage”; “The Project is not collecting any samples (except possibly a few in Europe, through the European regional committee)”; “the HGDP is a regionally organized project that remains entirely in the planning stages in most of the world.” (Emphases added.)

What is to be made of these hedged denials regarding the status of the HGDP? There are at least two rhetorical possibilities the nature and marked divergence of which reveals how value-bifurcation undermines robust normative critiques of proposed research projects. From the perspective of HGDP advocates, the need to secure funding while avoiding misrepresentation necessitated simultaneous claims that, although there was some limited work in progress, the HGDP itself was still a proposal and not under way. On the one hand, the HGDP as such had been neither authorized nor funded and, because funds were being sought precisely to initiate it, it could not be presented as already under way. On the other hand, selected work was under way that was either intended to contribute to the project or would eventually fall under it. For instance, the 1994 Annual Report of one lab (Julia Bodmer’s, a member of the HGDP International Executive Committee) notes: “As a contribution to both the 12th International Histocompatibility Workshop Anthropology Study and the Human Genome Diversity Project we have collected 160 samples from

individuals indigenous to the Orkney Islands.”

In the following year’s Annual Report, mention is made that “The anthropology study will be used as a pilot study for the Human Genome Diversity Project.” Moreover, because the existence of such ongoing funded research might well have enhanced the case for the fundability of the HGDP, the prudent advocate might have been disinclined to overlook it. As one commentator points out: “the exigencies of seeking funding require putting the best possible face on it.”

However, the danger was that this strategy might also derail assessment of the ethico-political issues which figure in research justification, allowing knowledge production to proceed without the benefit of normative critique. Indeed, this was the very danger courted when the National Science Foundation (NSF) issued its call for Pilot HGDPs before the National Research Council’s (NRC’s) appraisal of its normative implications was concluded. The worthiness of a proposed (pilot or otherwise) research project like the HGDP must not be assumed simply because limited work had been funded and was already under way. Some supporters, for example, defended it as involving a mere change of scale: “the work doesn’t constitute anything fundamentally new,” it is “merely a way to organize” the collecting of samples that has been going on for years.

The moral conclusion that such reasoning invites – that, therefore, the HGDP is morally innocuous and more a matter of bureaucratic efficiency than anything else – is an obvious non sequitur. Morally suspect research doesn’t cease being objectionable simply because it becomes better organized. Indeed, in the case of the HGDP, the contrary would seem to be true. As anthropologist Jonathan Marks observes, this would be “a large-scale, publicly visible, and highly funded ‘Project’” that not only permits, but encourages, a sample collection which is already morally problematic.

The adamant, but qualified, insistence of Greely and others that the HGDP was not really (or not very extensively) underway had a very different rhetorical force for HGDP critics, for whom it appeared as a gesture of

25 Ibid.
26 Noted by an anonymous referee of the journal Perspectives on Science: Historical, Philosophical and Social.
28 Marks, “Commentary,” 72.
mollification that served to weaken the force of their objections (nothing is happening yet, so why worry?) and by doing so to ease the funding process. These objections were political as well as ethical in nature, directed against the HGDP as a proposed program of knowledge acquisition. Above all, the HGDP was being critiqued as yet another manifestation of biocolonialism, one that seemed particularly oblivious to political critique. As John Liddle, director of the Central Australian Aboriginal Congress, contended:

If the Vampire Project goes ahead and patents are put on genetic material from Aboriginal people, this would be legalized theft. Over the last 200 years, non-Aboriginal people have taken our land, language, culture and health – even our children. Now they want to take the genetic material which makes us Aboriginal people as well.  

As already noted, resistance to the HGDP was so pronounced that many of its supporters were startled. This opposition ranged from concerns over the likelihood of commercialization, biopatenting, and continued exploitation of indigenous peoples, to the various impacts such knowledge acquisition might have on indigenous communities. The latter include internal disruption caused by controversies over sampling as well as by the clash of worldviews, and the danger to indigenous communities posed by the involvement in the HGDP of surrounding – typically hostile – nation-states, as well as by the threat of genetic manipulation and of indiscriminate access to the HGDP database. Nilo Cayuqueo, Director of the South and Meso American Indian Information Center (SAIIC), alludes to a number of these in his response to Greely:

The information you gather about our genetic make-up will be readily available to governments, foundations and corporations. For the past 500 years, these institutions have waged an unbridled war of oppression and genocide against our people. The implications are

31 Aroha Mead stated the concern here well:

Many states actively oppress indigenous communities. What mechanisms are in place to ensure that States do not use the HGDP to substantiate biases and objectives of government to undermine indigenous self-determination? If the HGDP relies on government funding, it almost guarantees a bias towards sponsoring government objectives which historically are counter-productive to indigenous objectives. (Mead, “Letter”)
potentially devastating for indigenous people all over the world... How are we going to be able to control these institutions from patent- ing and thereby owning the rights to our genetic material enabling them to make profits from our own blood?  

Along with many others, SAIIC called for a halt to the HGDP “until all of the moral, ethical, socio-economic, physical and political implications have been thoroughly discussed, understood and approved by indigenous peoples.”  

Their objections were plainly directed against proceeding with such knowledge acquisition.

By insisting that the HGDP was still pending and not under way, such normative critiques – which would otherwise threaten to impede the acquisition of knowledge in the first place – might be rhetorically deflected. The porous filter of the pure/applied science distinction could be put to work. As earlier with the HGP, “anticipations of ethical, social and legal implications” would take their place not “in assessing the desirability” of the HGDP itself, “but in identifying limits to its future applications.”  

Greely set the agenda for his Ethics Subcommittee as follows: “the creation of model protocol, discussing ethical, legal and practical issues in collecting DNA, and a workshop on the best methods to protect the rights of sampled populations in the collected DNA.”  

Because, he acknowledges, commercialization would be hard to exclude, materials transfer and database access agreements would be set in place to minimize it. The draft model protocol outlines the ethical issues that those engaged in DNA sampling for the HGDP will encounter. The longest section deals with informed consent procedures; one of the shortest is addressed to questions of ownership and control.  

Thus although the negative critiques would be contained, and managed at the level of knowledge application, positive assessments of what would be gained from the HGDP would still go through, reflecting favorably upon the case for knowledge acquisition. Substantive political and ethical critiques of the HGDP would be diverted from the acquisition...
of such knowledge to its use, and would there be treated via document and committee as a matter of regulation (contractual agreements) and procedures for obtaining informed consent (the Protocol).

Racism or Representation?

In its later incarnations, the Diversity Project adopted a rhetoric of justification which attempted to obscure even the fact that those who would be sampled were predominantly indigenous. In response to indigenous opposition and the need to secure funding, supporters modified their arguments and rhetoric. Potential biomedical applications played a greater role. Although, if biomedical applications were indeed to be developed, then the two groups most likely to profit would be the corporations (which would market the therapeutic products) as well as those individuals with the diseases in question able to afford the genetic therapy or pharmaceuticals required. Members of sampled indigenous populations would be most unlikely to be among the latter.

Among the HGDP’s “important practical uses” was “the application of the data to the study of disease”; the HGDP was held to be “an essential basis for genetic epidemiology.”37 Most notably perhaps is the fact that the HGDP began to characterize itself as a counter to racism. (Not surprisingly, the United Nations Educational, Scientific and Cultural Organization’s [UNESCO’s] International Bioethics Committee – which refused to endorse the HGDP – described this claim as the “most debatable” made by its proponents, arguing that “the prejudice that gives rise to racist and eugenic attitudes tends to pervert scientific results to its own ends.”38) It did this by presenting itself as wanting to understand the diversity and unity of the entire human species or the whole “human

37 Greely, “Summary Document.” Philip Bereano argues that, if saving lives through medical advances were truly the goal the dominant society is seeking, then it would be funding efforts to reduce infant mortality instead. But that this issue is . . . essentially one of power, is illustrated by the fact that the vast majority of . . . infant deaths . . . occur in ghettos, barrios and reservations to women who do not have nearly the same power to influence Congressional investment choices as do academic biologists and Wall Street venture capitalists. (Philip Bereano,”Message posted to Native-L on 31 October 1995.” Available online at: http://nativenet.uthscsa.edu/archive/nl/9511/0014.html.)

family.” According to the FAQ, the scientists involved with the HGDP were concerned that most human genome research concentrates only on persons from the major ethnic groups in the industrialized countries. Indigenous groups are not being served – and this deliberately ignores their importance as members of the human species.

The HGDP then was necessary for moral reasons. In fact, failure to pursue it would be morally suspect, according to geneticist Kenneth Kidd: “We’re not trying to exploit people; we’re trying to include them. It’s racist to avoid the totality of humans.” Cavalli-Sforza commented that “I know that a race gene does not exist. And that’s what the project will show.” Greely, meanwhile, observed:

We can acknowledge the diversity of our species only by studying that diversity, not by pretending that an American genome is “the” human genome . . . studying the diversity should help us see better how closely related all humanity is – that we are, in literal fact, an extended family.

To reinforce this supporting argument, and to counter charges of racism, the HGDP also reconstructed its subjects. The initial call referred to “isolated human populations” and “indigenous populations of great interest.” Those populations specifically mentioned were all indigenous, as were those listed on the HGDP’s list of more than 700 groups to be prioritized in sampling. The second HGDP workshop at Penn State spoke of “Isolates of Historic Interest” because they represent groups that should be sampled before they disappear as integral units so that their role in human history can be preserved.

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41 Kahn, “Genetic Diversity Project,” 721.
However, as the HGDP came under increasing attack for “targeting” indigenous populations, it offered reassurances that, despite reports, it was “not an effort to collect samples from isolated populations in danger of disappearing (but) intends to take a representative sample of all human populations . . . No group is necessarily excluded.” Greely denied that the HGDP is “ABOUT indigenous populations, or, even worse, ‘disappearing’ indigenous populations. The Project is sampling the genetic diversity of ALL of humanity.” However, although it was true that HGDP scientists never “excluded” any particular group(s), it is also true that indigenous peoples were the focus and scientific “interest” of the HGDP. It was precisely the HGP’s failure to include such groups that motivated the HGDP in the first place. This rhetorical move, like the others we have examined, is an effort to depoliticize and contain normative critiques within the facilitating space provided by applied ethics. It is flanked by a simultaneous effort to recruit: The former Isolates of Historic Interest and the HGDP are no longer “subjects” of “scientists” but “participating populations” involved in a “partnership.”

The emphasis and wording of the Diversity Project’s goals were altered. Not only, its proponents insisted, would it increase knowledge in valuable ways, it would do so in one particular way. The Diversity Project seeks to understand the diversity and unity of the entire human species or family. Without it, science will characterize “the” human genome, with its historical and medical implications, largely in terms of what is known from a small sample of people of European ancestry . . . At a time when we are increasingly concerned with preserving information about the diversity of the many species with which we share the Earth surely we cannot ignore the diversity of our own.

Bodmer described it as a “cultural obligation of the Human Genome Project.” Ken Weiss, head of the North American Diversity Project, echoed his point: “If we don’t go ahead with this . . . when the Human Genome Project is done, a Navajo, say, will look at those results and

46 Human Genome Diversity Project, “FAQ.”
49 Human Genome Diversity Project, “FAQ.”
ask, ‘Why did they bother? How well does that represent me?’”51 As one Diversity Project scientist angrily remarked of the indigenous opposition: “They should be grateful to us.”52 The Diversity Project, then, is allegedly necessary for moral reasons. It is, in fact, a weapon against racism: “We’re not trying to exploit people; we’re trying to include them. It’s racist to avoid the totality of humans.”53 Just as the HGP was held to provide a solution to homelessness, the Diversity Project was now held to provide a solution to racism.54

Yet the Diversity Project is avowedly focused on population-based differences. One of its objectives is to locate “those relatively few genetic markers which are concentrated in specific ethnic groups due to random mutation or the interaction of biological and cultural adaptations in specific ecological niches.”55 Given the nature and scope of the possible abuses, concerns about them should have been taken seriously and faced directly, although that would have involved situating the Diversity Project on a continuum of scientific research from which it wanted to distance itself. Several Diversity Project scientists had pointed to their “established track records in human rights” to defend themselves from charges of racism. According to Marc Feldman, “All of us have worked throughout our lives in an antiracist framework. Our political credentials are in order.”56 All the more reason then to expect more by way of political awareness. But the pure motives, faultless intentions, and previous good works of all those involved are plainly beside the point. They will not alter the fact that such work is embedded in cultural politics, that it bears a considerable historical burden, and that it lends itself to appropriation and abuse by individuals, organizations, and

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52 This comment was made at a 1997 conference on genetics by a scientist working with one of the Diversity Project’s main proponents.
54 According to Daniel Koshland: “The homeless problem is tractable. One third of homeless are mentally ill – some say 50%. These are the ones who will most benefit from the Genome Project.” Cited in Jon Beckwith, “Thinking of Biology: A Historical View of Social Responsibility in Genetics,” Bioscience, 43 (1993): 330.
56 Gutin, “End of the Rainbow,” 73. Jenny Reardon speaks of a “mismatch between organizers’ understanding of themselves as good, anti-racist scientists, and critics’ charges that they were furthering colonialism and practicing bad science.” She attributes these divergent perceptions partly to the failure of the proponents (scientists, policy makers, and ethicists) “to bring into a sharp focus the intertwined epistemic and political contexts in which biological science is now asked to operate.” Reardon, Race to the Finish, 159.
governments. It is pointless to impute intent here (i.e., deliberate political co-optation by individual scientists and their supporters, or a conscious effort to rhetorically deflect “troublesome” normative critiques). Doubtless there are instances of that, but it is neither necessary nor productive to assume or argue it. Far more interesting – and worth resisting – is how such rhetoric operates in the absence of intent, through the convergence of interests, ideology, inadequate analyses, and institutional constraints.

The characterization of the Diversity Project as a solution to racism was coupled with reassurances that, despite assertions to the contrary, it was going to sample everyone, excluding no one. As with Greely’s denials, all that can be said about such reassurances is that they were painfully transparent instances of rhetorical spin. Their adamant, vocal rejection by indigenous peoples not only jeopardized the possibility of locating cooperative populations to sample, it badly damaged the Diversity Project’s public image, and thereby the likelihood of funding. Such responses are an unconvincing rhetorical two-step: Retreat into vague, inoffensive generalities about the “whole human family” and hope no one notices that indigenous peoples are ninety-nine percent of the diversity sought; emphasize talk of unity in a project that will study difference, and hope that people will forget the sorry history of western science’s obsession with racial, class, and gender differences. As Ruth Hubbard maintains,

Basing differences between the so-called races or between women and men, as groups, in “genes” simply uses that status-laden word to legitimate ideological constructs...scientists have often made it appear as though differences in power between individuals or groups of people were inevitable and natural results of biological difference, and hence of genes.58

Contextualizing the HGDP

Biological explanations, as Dorothy Nelkin observes, “do political work, ‘creating the rules for belonging and exclusion.’” From the Late Enlightenment on, racial differences have been singled out as “crucial aspects of

57 Human Genome Diversity Project, “FAQ.”
59 Nelkin, 122.
reality” by those studying human variation, and “an extensive discourse on racial inequality began to be elaborated.” In the nineteenth century, sex and gender differences began to be emphasized as well. The more egregious episodes in the history of the study of human variation are legion.

The early-twentieth-century eugenics movement advocated sterilization of the “genetically unfit” and influenced medical practice, policy formation, and legislation – including the 1924 Immigration Act, which restricted immigration from the allegedly “biologically inferior races” of Southern, Central, and Eastern Europe. Initially influential in the United States, it soon spread abroad – most especially to Nazi Germany. Nineteenth-century craniometry was seen to prove Nordic superiority by assuming it. Its most renowned practitioner was an American, Samuel Morton, who used his massive collection of skulls to “illustrate” the inferiority of American Indians, among others. The history of intelligence testing is riddled with efforts to find a genetic basis for presumed human differences. The early class-obsessed (and fraudulent) work of Cyril Burt had a lasting impact on British educational policy, and the more recent race- and class-fixated efforts of The Bell Curve’s Herrnstein and Murray nurture the political agenda of the Far Right. Following World War II, and largely as a reaction to the eugenics movement, human genetic variation research redefined the concept of race, in terms of populations, a move that was “deeply political, cultural, intentional and interested”:

It was an explicit strategy by geneticists to distance “good” science from the inherently political, racist and genocidal ends that eugenics had been put to during the war by the Nazi government.

65 Barker, 577, 578. For a good discussion of early efforts to account for human diversity, as well as of that of the HGDP, see Margaret Lock, “Genetic Diversity and the Politics of Difference,” Chicago-Kent Law Review, 75 (1999).
There also has been an extensive, ongoing program of research into sex differences, notably in the areas of aggressivity, brain-hemispheric asymmetries, and mathematical/visuospatial ability, which reinforces long-standing unfounded assumptions about female “deficiencies.”⁶⁶ Where race, class, and gender differences have not themselves been the focus of scientific research and medical practice, they have figured heavily in other ways. In the Tuskegee syphilis experiment, race and class enabled the dismissal of proper informed consent procedures.⁶⁷ Gender and ethnicity were crucial in similarly subverting informed consent by American Indian women indiscriminately sterilized by the Indian Health Service during the 1970s.⁶⁸

This is the broader sociopolitical and historical context of research into human differences. It is the inheritance of the Diversity Project, however unwanted by, and at odds with the intentions of, its proponents. If they wished to disown it, they would have had to proceed very differently than they did. Rhetorical two-stepping like the above was exactly how not to proceed. It was an attempt to further shield the Diversity Project from moral and political critique. The indigenous status, and precarious state, of many desired subject populations was cloaked, and the term “human groups” substituted for “indigenous peoples.” Project supporters stressed the openness and public nature of their planning, but this rhetoric hid and manipulated. It also added to the offensiveness of the charge that indigenous peoples misunderstood and overreacted to the Diversity Project. According to the report of the International Bioethics Committee, the World Council of Indigenous Peoples “mistakenly thought that the [Diversity Project] was aimed exclusively at sampling from endangered populations, which it should not be.”⁶⁹ Indeed it should not have been, but not only did the reports in scientific journals describing the Diversity Project, as well as the scientists’ statements cited in those reports, give this inescapable impression, but it remained the case that the populations which would

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be approached, largely with the assistance of anthropologists, would be almost exclusively indigenous. The rhetoric of the Diversity Project simply masked that fact. Even the International Bioethics Commission report noted that opposition was “based upon more than misunderstandings . . . or antiscience attitudes, but ‘is a clash of philosophy and cultural insight.’”  

Indigenists emphasized this last important point, but Diversity Project supporters had little to say in response. Aroha Mead observed that “many in the [Diversity Project] have the mistaken view that the reason for indigenous opposition . . . rests in lack of understanding of the Project’s aspirations, and confusion over minor details.”  

The critiques were directed to something quite fundamental – to the clash of knowledge and value systems that lay at the heart of this controversy. Although Mead’s discussion is framed in terms of Maori beliefs, it resonates with the basic commitments of many other indigenous peoples. The concept of the human gene on which the Diversity Project relies, she notes, is at odds with the indigenous understanding of what a human gene is, of what and whom it represents, of what and for whom its purpose is determined, and of who the “owner or guardian” of human genes is. For the Maori people, and many others, the human gene is genealogy. In Maori, “a gene” is translated as iratangata – “life spirit of mortals.” More commonly whakapapa genealogy is used; it is the basis for Maori connecting with themselves and others. Because a gene, or genome, is imbued with a life spirit that has been handed down by the ancestors and is passed on to future generations, it is not and cannot be the property of individuals. It is part of the heritage of families, communities, tribes, and entire indigenous nations. Mead stressed that the indigenous and western scientific philosophies differ on this fundamental point . . . it is the difference in understanding of the origin of humanity, the responsibility of individuals, and the safety of future generations which sits so firmly at the core of indigenous opposition to the [Diversity Project] . . . this type of research proposes to interfere in a highly sacred domain of indigenous history, survival and commitment to future generations. 

71 Mead, “Letter,” 49. I draw freely here on Mead’s discussion in this letter.
72 For more on this, see Roma Mere Roberts and Peter R. Wills, Understanding Maori Epistemology, in Helmut Wautischer (ed.), Tribal Epistemologies (Surrey, United Kingdom: Ashgate Publishing, 1998).
73 Ibid.
Debra Harry concurred: “We don’t view our genes as protein actions ready to be interpreted; for us our genes are sacred.”

The only response Diversity Project proponents made to this was that no one would force any population to participate. If a particular group’s understanding of the natural world conflicted with that embraced by the Diversity Project, it could refuse to give consent. Presumably, if it did consent, then the Diversity Project would not be responsible for any unfortunate impacts on that group’s belief system. This myopic view of moral responsibility ignores how unequal relations of power compromise the (western) practice of informed consent, and furthers scientific aspirations at the expense of indigenous peoples: “Given the isolation of many of the populations involved, their non-literacy, and lack of acquaintance with a cosmology grounded in molecular biology, obtaining informed consent will be a contrived exercise, which, aside from human rights issues, may have some unforeseen results.” It may also have undesirable but foreseeable results. Project proponents were well aware of indigenist concerns about the commercial exploitation of genetic materials. Intellectual property rights, one noted, have provoked some misunderstanding:

The Project was viewed as similar to plant prospecting trips, that had enriched the genetic stock available to western seed or pharmaceutical companies, and ultimately their profits, without providing any benefit to the people who had nurtured and domesticated those plants.

It is precisely this connection that indigenists emphasized by situating the Diversity Project along a continuum of previous and ongoing practices

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75 This has happened on various occasions. Consider the U.S. Government Accountability Office’s (GAO’s) review of the consent procedures used by the Indian Health Service from 1972 through 1976, when extensive sterilization operations were performed on American Indian women across the United States. Charging that the procedures lacked the basic elements of informed consent, the GAO noted that the women were not adequately informed of the advantages and disadvantages of sterilization; the form only summarized the oral presentation; and the form omitted the usual information at the top of the page notifying the patient that federal benefits would not be taken away if they did not accept sterilization. See Michael Sullivan DeFine, “A History of Governmentally Coerced Sterilization: The Plight of the Native American Woman” (May 1, 1997). Available online at: http://www.geocities.com/CapitolHill/9118/mike2.html.
77 Greely, Message of October 12, 1993.
of cultural imperialism, in which the resources (spiritual, material, and genetic) of indigenous peoples have been seized and commercially exploited. To put the Diversity Project in perspective, Philip Bereano suggests,

Note that a First World society which does not provide indigenous communities with even the rudiments of public sanitation, preventative medicine, or curative treatments . . . is going to ask these communities to give us something which may be beneficial for our health care. After having dominated most of the mineral and vegetative resources of indigenous peoples, we are now talking about turning on their very bodies as the ultimate resources to exploit.\(^7\)

**Why Patenting Is Not an Answer**

Diversity Project advocates insisted that it was not a commercial enterprise, that it sought knowledge rather than profit (although it never agreed to refuse corporate funding). Some, however, admitted the possibility of commercialization and contended that patenting would provide “part of the answer [to biocolonization], not part of the problem.”\(^7\) They proposed that patenting be allowed only with prior informed consent. The participating population would decide its position on patenting. Materials transfer and database access agreements would be used to contractually bind parties who take information from the Diversity Project’s repository and database and to ensure that they observe whatever restrictions the population wanted; all of this would then be incorporated into informed consent documents. This proposal reflects the moral and legal constraints operative in the dominant culture, and there were a host of problems with it, as indigenist critics made clear.

a. The very concept of patenting genes clashes fundamentally with indigenous knowledge and value systems, as we have already seen in the case of the Maori. It is expressed as well in a number of the major statements of opposition to the Diversity Project issued by indigenous organizations: “We oppose the patenting of all natural


genetic materials. We hold that life cannot be bought, owned, sold, discovered or patented.”

b. The proposal still forces an intellectual property regime on indigenous peoples. Intellectual property rights are a western legal concept developed to facilitate private ownership of intangible resources and to protect individual, technological, and industrial inventions. The price of protecting indigenous knowledge with western intellectual property is, Chidi Oguamanam notes, the “forced epistemological assimilation” of that knowledge. Indigenists argue that intellectual property rights are inappropriate instruments to impose on indigenous peoples’ communitarian cultural and legal systems. As an Aboriginal activist notes:

We assert that our identity and our rights are not reducible to the rights of individuals... With its cult of the individual and its emphasis on individual rights, non-indigenous people in the western world have failed to acknowledge the collective nature of indigenous societies, and have provided inadequate protection for the group rights of peoples.82

The Working Group on Traditional Resource Rights has proposed alternatives to intellectual property rights which attempt to determine the extent to which existing international customary law and practice can be used to defend indigenous knowledge and biogenetic resources. Indigenous peoples, indigenous legal systems, and concepts of property rights are guiding this debate.

c. No enforcement mechanisms were in place, or proposed, for ensuring that the materials transfer and database access agreements were honored. Brett Shelton, Native attorney and former policy analyst for the National Indian Health Board, asks “But who will enforce the contracts? Why should we trust the HGDP to enforce them for us?” He notes that, if someone misused the samples or violated the contract, it was unclear what, if anything, could be done about it:

80 “Declaration of Indigenous Peoples of the Western Hemisphere Regarding the Human Genome Diversity Project,” available online at: www.ipcb.org.
The protocol is considered a model, yet it is not going to be helpful in protecting tribal rights. To have something like this be the definitive example on how our rights will be protected is not comforting at all – in fact, it’s scary. We have some serious things to be concerned about, and this Protocol is not going to help at all.²³

The proposal, then, would not prevent biopiracy. Genome scientists declared the patent system the “‘mechanism of excellence’ for commercializing the results of the Human Genome Project.”²⁴ Given current biopatent trends, and the potential for corporate biotechnology funding, patenting would likely occur.²⁵ Researchers associated with the Diversity Project may agree not to patent indigenous genetic material, but others would not be similarly bound. Lest such an “end-run” seem far-fetched, note that it was actually proposed at one of the Diversity Project’s workshops on “Ethical and Human Rights Implications”:

It would be useful to the Diversity Project to say, from the beginning, that no patents will be sought for genes taken from the Project’s samples. A firm interested in patenting the gene could always go back independently to the country where the gene was found and make whatever financial arrangements were appropriate, but that would not implicate the Project.²⁶

Even the President of the American Type Culture Collection, where the Diversity Project samples would be stored, expressed doubts that codes of ethical conduct, or even the law in this regard, could be successfully enforced. Raymond Ciphus believed that there would be a black market on this material, nationally and internationally:

²³ Brett Shelton, cited in Debra Harry “Tribes Meet to Discuss Genetic Colonization.” Available online at: www.ipcb.org.
²⁵ Recent empirical research, however, suggests that the pace of patenting and commercialization is not as fast as some have feared. Russel Barsh argues that, so far as intent or motivation goes, academic career promotion and intellectual curiosity rather than profit are driving human genetic diversity research. (See his “Pharmacogenomics and Indigenous Peoples: Real Issues and Actors,” Cardozo Journal of International and Comparative Law, 11 (2003): 382.) He also notes that patents with indigenous origins were largely the result of data in publications of academic researchers placed in the public domain. (See Russel Barsh, “Intellectual Property and Indigenous Peoples,” American Society of International Law Proceedings, 95 (2001).)
I think you are going to see materials being taken, tissues processed and cells produced and I don’t see any way that patent laws and policing by the traditional methods are... going to be able to control this.  

Under these circumstances, as one lawyer has suggested, a truly fair disclosure on an informed consent form might well read as follows:

We are gathering this data for the benefit of people other than you. It is likely that you will have negative consequences from this and no gain. We are asking you to give to us, with little or nothing given to you in return, and we expect you to absorb all losses that may accrue to you, and all of your people, from this project [both foreseen and unforeseen] without any liability on our part.

d. There are serious problems with informed consent documents, especially in these contexts. One is a lesson from history and treaty making that suggests that prior informed consent documents would not serve to protect indigenous peoples: “This was exactly what did not happen in many First Nations/Wasichu treaty relationships[,] ultimately resulting in the theft of inherent rights... because it was beyond comprehension what might be important in the future.” The proposal also imposes a western model of individualized consent on indigenous peoples. How exactly does one secure the informed prior consent of entire indigenous populations or of the communities that make them up? Who will determine whether, and on what basis, a certain number of individuals must consent, or only a single “leader”? Who within a given community is authorized to give consent for research that implicates everyone? Is it a tribal governing committee – with no mandate for ethical decisions – or a spiritual leader? For native North American peoples, it was proposed that an officially recognized tribal government be the decision-making body. Anyone familiar with current controversies in Indian Country, and the

88 Interview with Alan W. Clarke, J. D., in Chassell, Michigan (December 1, 1997).
struggle between progressives and traditionals over issues such as gambling casinos and nuclear waste repositories, will recognize in this a horribly divisive scenario. As Mead states: “the [Diversity Project] and other similar-type activities can serve to divide, and cause irreparable damage to the ability of indigenous communities to trust each other, let alone to trust others.”

The divisiveness would only be compounded if government officials of the nation-state in which the indigenous nation is located were given a role in deciding who has the authority to give “consent” to speak for the people. Given the historical relationships between many nation-states and indigenous peoples (e.g., Iraq and the Kurds, or Guatemala and the Mayans) this could be disastrous; this difficulty would only be exacerbated by the Diversity Project’s regional organization.

e. Communication difficulties will undercut the basis for informed consent. There is a massive tangle of western institutions, beliefs, and values built into human genetic research, specific collection practices, libraries of cell collections, instruments such as materials transfer and database access agreements, intellectual property law, and royalties. How will the Diversity Project be explained? Anthropologists are touted as essential, but their own interests may figure in important ways. Will their research grants and careers be tied to success in sampling? How extensive and explicit will the information conveyed be? Finally, what of previous and current sampling? In some cases there has been no informed consent at all, much less that obtained in the manner outlined in the proposal. Will the Diversity Project allow access to this data?

Conclusion

The Diversity Project’s violation of fundamental principles of social justice was manifest. The benefits of the Diversity Project to indigenous peoples were minimal to nonexistent, yet they were the ones who would bear whatever harms resulted, directly or indirectly, from Diversity Project activities

90 Mead, “Letter from Aroha Mead.”
and from the misuse of the data collected. Debra Harry drew on the 1964 Helsinki Declaration’s injunction that “in research on man, the well-being of the subject takes precedence over science and society” to argue for a halt to the Diversity Project on the grounds that “indigenous people not only will not benefit from it, but may experience increased discrimination as a result.” 91

This is not an idle worry, given the history of western science when it comes to the study of human differences and the ease of accessing such a database. It will not do for Diversity Project scientists, from their comparative position of privilege and power, to invoke some dubious principle of double effect and accept only responsibility for the research consequences they intend and foresee, while eluding responsibility for the unintended consequences of their work which indigenous peoples predict. For one thing, the “experts” on the negative consequences of western intervention in indigenous societies are people from those societies, not western population geneticists. Predictions of indigenous societies must be given significant weight. For another, many of these unintended consequences are not only foreseeable but also probable, given the present surge in life-form patenting (and profiting), the biopiracy precedents already established in agriculture and botanicals, and the extensive human tissue trade. 92 As John Moore (a Seattle businessman who lost an infamous California Supreme Court case which declared that he had no ownership rights over cells his doctors removed from his body and patented) asked during a 1996 meeting of the National Academy of Sciences Committee on the Diversity Project: “Do you think a system that could not protect me will protect the rights of peoples or individuals that live in other countries?” 93

Similar concerns were voiced by the UNESCO International Bioethics Committee in its refusal to endorse the HGDP. In their long list of criticisms of the Diversity Project, they protested that: “the enthusiasm of the project’s supporters for scientific results has led to the neglect of

wider issues, in particular human rights . . . although HGD has ‘expressed urgency’ in collecting samples from peoples in danger of cultural and physical extinction, it had not expressed concern about their extinction per se.”

The debate over the HGDP illustrates how its indigenist critiques not only demonstrated the conjoined operation of value-neutrality and value-bifurcation in the new imperial science, but also directly challenged it. Politics (the “social and collective”\footnote{Elizabeth Grosz, \textit{Sexual Subversions} (Sydney, Australia: Allen & Unwin, 1989): xvii.}) does not begin where ethics (“the behavior of individuals”\footnote{Ibid.}) ends. Ethics never finds its “limits.” According to one Iroquois leader, Joagquisho (Oren Lyons): “Every question that is political is also moral. Every question. And you have to answer it morally.”\footnote{Oren Lyons, \“R.C.A.P. Public Hearings\” (Akwesasne, May 1993). Available online at: http://sisis.nativeweb.org/mohawk/ovide.html.} Moreover, issues of power in ethics, especially in the ethics of science, are rarely, if ever, absent. They continue to be played out vividly and resolutely in ongoing struggles over biocolonialism.

In October 1997, the NRC finally released the results of its 30-month-long study of the HGDP proposal, rejecting it as ethically, legally, and scientifically inadequate: “Following an exhaustive examination, the committee found the proposal does not clearly explain the purpose of the project or provide the necessary safeguards for protecting participants.”\footnote{RAFI, \“Scientific Review Rejects the HGDP,\” (25 October 1997). Available online at: http://www.etcgroup.org/en/materials/publications.html?pub_id=436.} Nevertheless, during this time, the NSF had continued to fund the HGDP; its Physical Anthropology Program almost doubled its support for this type of research, allocating $1 million, or 52\% of its grant monies to support ten HGDP-related projects.\footnote{RAFI, \“US Funding of Human Biodiversity Collections.\”} It was a mixed outcome. The determined, articulate opposition of the HGDP’s critics and subjects had at least temporarily shaken the effectiveness of a rhetoric of research justification based on value-neutrality and value-bifurcation, yet, although the research would not proceed with all due haste, it would continue. The NRC committee recommended both that any future diversity study be under United Nations supervision (something the HGDP had steadfastly resisted) and

\footnote{Butler, \“Genetic Diversity,\” 373.}
that limited funding be approved for (non-HGDP) diversity collection. As Hope Shand, Research Director of Rural Advancement Foundation International (RAFI\textsuperscript{100}), noted:

That would result in a piecemeal approach that is inconsistent with the NRC’s call for a complete research protocol...to be in place before consent procedures, much less collection, can start.\textsuperscript{101}

And so HGDP-related work proceeded apace, without normative safeguards in place.

Perhaps one of the most valuable counters to the justificatory rhetoric advanced by those promoting the HGDP was the persistent, emphatic, and thorough contextualization of this research initiative. Normative critiques of the HGDP invariably undermined the tendency of its advocates to abstract, isolate, and immunize the project from history and politics. The sidestepping of such issues was neither subtle nor oblique. The HGDP’s official FAQ stated that if sampling is too long delayed, some human (i.e., indigenous) groups may disappear as discrete populations due to urbanization or loss of language or other characteristics that distinguished them as a separate group,\textsuperscript{102} and the initial Call for a Survey observed that “isolated human populations are being rapidly merged with their neighbors”:

Population growth, famine, war and improvements in transportation and communication are encroaching on once stable populations...destroying irrevocably the information needed to reconstruct our evolutionary history.\textsuperscript{103}

\textsuperscript{100}RAFI was an advocacy organization that, at the time of the HGDP debates, was devoted primarily to issues of biodiversity and biotechnology. It, and the research it disseminated online via the RAFI Communiqué, played an influential role in these debates. It has since expanded its scope and undergone a name change. See “RAFI and RAFI-USA Announce Plans of Name Change for Globally-focused RAFI,” 5 February 2001. Available online at: http://www.etcgroup.org/en/materials/publications.html?pub_id=282. The RAFI Communiqués crucial to the HGDP debates can now be found in the archives of the ETC Group, at http://www.etcgroup.org/en/archives.html.

\textsuperscript{101}RAFI, “Scientific Review Rejects.”


\textsuperscript{103}Luca Cavalli-Sforza, et al., “Call for A Worldwide Survey,” 490.
Such priorities and callous dismissals of the many ways in which oppression historically has impacted, and continues to impact, the survival and well-being of indigenous peoples are in no small part the legacy of value-neutrality and value-bifurcation. So too is the failure to realize that – because contemporary biotechnoscience sustains that oppression by commodifying and patenting indigenous genetic resources – proposals like the HGDP cannot suppose that they are unanswerable to this political context. The response that “We are scientists, not politicians” is neither responsible nor convincing for bioscientists, whose work is commercialized – whether by themselves, by governments, or by the seed and drug industries – almost immediately upon completion.

Like most ideological commitments, value-neutrality, value-bifurcation, and the pure/applied science distinction are most powerful when most submerged. They are then most able to ensure that criticisms will not reach all the way to knowledge production, and will be managed and reformulated at the level of knowledge use. The resulting rhetoric of research justification can be difficult to detect, analyze, and assail. Yet indigenist critics of the HGDP did so consistently, and in ways that brought these ideological commitments to the surface where they could be faced and accounted for. Although the impact of these critiques forced some HGDP advocates to acknowledge, and look more closely at, the political face of science and of knowledge production, others have found the task too discomforting. Too convinced, perhaps, of the primacy of their own good intentions and of the severability of bioscience initiatives like the HGDP from unequal relations of power, they enfolded themselves in a justificatory rhetoric which facilitated selective responsibility for the practice of science as it reinforced extant power relations.

104 A case in point: Not a single representative of the thirteen-member North American Committee of the HGDP would attend a 1998 conference that brought together tribal leaders, elders, tribal legal advisors and educators, scientists, and health officials to discuss genetic research and native peoples. This, despite repeated invitations by its indigenous organizers, and despite the fact that the Diversity Project received foundation funding “for the specific purpose of communication with tribes” (Debra Harry, “Tribes Meet”). The reason? They objected to the conference’s title and to the fact that they would be given no more time than other speakers to present their case. According to Greely, “anyone attending the conference on behalf of the HGDP would be cast, unfairly but irrevocably, in the role of arch villain and ‘bio-pirate.’” (Ibid.) “The conference you organized was biased,” the Chair of the North American HGDP Committee, John Moore, told the organizers, “so even if we had been free to attend, we probably would not have done so.” (Ibid.)